The White House Conference on Handicapped Individuals

HEALTH CONCERNS

State White House Conference Workbook

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The White House Conference on Handicapped Individuals

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Dear State White House Conference Delegates:

It is with admiration and appreciation that we welcome your participation in this State White House Conference.

From the beginning of White House Conference activities, we have placed great importance on the deliberations of State Conferences.

The recommendations emanating from your Conference will form the basis of actions at the White House Conference itself.

We encourage each delegate to use this Conference to impact in new ways on State and local governments, the private sector and the Federal Government to bring greater independence, dignity and full participation into community life for all mentally and physically handicapped individuals.

We wish you great success in an endeavor that will benefit handicapped individuals for years to come.

Sincerely,

Henry Viscardi

Dr. Henry Viscardi, Jr.
Chairman, National Planning
and Advisory Council

Jack F. Smith

Jack F. Smith
Executive Director

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OVERVIEW
THE WHITE HOUSE CONFERENCE ON HANDICAPPED INDIVIDUALS

The mission of the White House Conference on Handicapped Individuals is comprised of three goals:

-- to provide a national assessment of problems and potentials of individuals with mental or physical handicaps;

-- to generate a national awareness of these problems and potentials; and

-- to make recommendations to the President and Congress which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

The White House Conference on Handicapped Individuals was authorized with the passage of Public Law 93-516. Title III of that law stated that there were some "seven million children and at least twenty-eight million adults with mental or physical handicaps," and that "it is of critical importance to this Nation that equality of opportunity, equal access to all aspects of society and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps."

Toward that end, the President was authorized to call a White House Conference which would "develop recommendations and stimulate a national assessment of problems, and solutions to such problems, facing individuals with handicaps." Announcement of the Conference was made by the President on November 22, 1975, with the date for the National Conference set for December 1976, and then changed to May 1977.

The result of the White House Conference should be new advances by and for handicapped individuals, with this movement picking up momentum following the publishing of recommendations. If the recommendations and implementation plan are to be instrumental in generating that momentum, they must emerge as a consensus from a broad base of support. The purpose of the National Conference is to become a focal point for such a consensus.

For the National Conference to be successful, it must be representative of the same base of support which is needed later in carrying forward the recommendations. First, it is especially critical that the energies and ideas of handicapped people be engaged. At least 50 percent of the State delegates to the White House Conference will be handicapped, and 25 percent, parents or guardians of handicapped individuals. Professionals who provide services and others from business, labor and government who are interested in the problems of the handicapped will attend.

The criterion for a successful Conference also includes the opportunity for free participation by the delegates. At the same time the deliberations must be focused on what already has been defined as key issues.

To meet the goal of national awareness, the Conference and the issues must have good public visibility. Since the National Conference is necessarily limited in the number who can participate, it is well to include as many interested individuals as possible in defining the issues and providing the preliminary national assessment leading up to the National Conference.

Among the ways to secure this greater involvement and to channel needs and recommendations on issues to the delegates at the National Conference is through meetings at the state and local levels. This approach will also assure that attention is drawn to the actions that can be taken at the local and state levels to assist handicapped people in meeting their goals. The White House Conference activity should focus on recommendations for action by all sectors at all levels of national life, and not just by the Federal Government.

Our strategy, then, is to encourage the sponsorship, locally, of forums at which primarily handicapped individuals can introduce their views into the Conference process. At the state level (including the District of Columbia and the territories), preliminary White House Conferences will be held as intended by Congress. Reports of findings from both these types of events will be channeled into the National Conference for review and discussion prior to final recommendations.

In order to assure that local and state reports lend themselves to summarization for National Conference delegates and for the final report, a standard format has been developed for reporting. In addition, "awareness papers" have been written by experts in the field and given to leaders of State Conferences. Five broad areas cited by Congress are covered: health, educational, social, economic, and special concerns. These papers have initiated work on the national assessment goal. They define the barriers faced by people with

various handicaps and review what we already know about how those barriers can be overcome or minimized.

To get the kind of involvement necessary to generate national awareness foreseen in the Conference goals, we will enlist every major national organization and government agency to take an active part in the Conference activities before, during, and after the National Conference itself. Members of Congress and their staffs will also be involved to maintain their support.

In support of all these activities, and overlaying them in pursuit of the national awareness goal, will be a public affairs program.

With sufficient administrative support, we believe this strategy can be implemented and will be successful in creating the climate and the specific steps necessary to enable handicapped individuals to realize their potentials as contributors to American life.

The final White House Conference report to the President will offer very specific solutions to problems facing individuals with handicaps, and an implementation plan to the President and Congress will insure follow-up of Conference recommendations.

DEFINITIONS

1. Alternate -- An appointee from a State as an observer to the National White House Conference who may, at the appointment of the State White House Conference Director, fill a vacancy as an official delegate when an official delegate is unable to attend.

2. Awareness Paper -- Topical material, applicable to an assigned subject area, researched and organized in order to establish the foundations for informed Conference discussion and resolution of the vital issues affecting all handicapped persons at the local, State and National levels.

3. Conference Plan -- The three major goals of the Conference and the objectives and strategies necessary in order to achieve these goals.

4. Consumer -- A handicapped individual or a parent, guardian, sibling, or spouse of a handicapped individual.

5. Delegate -- A representative to the Conference who is the only Conference participant to hold voting privileges.

6. Delegation -- A group of Conference delegates selected to represent other individuals at the National Conference.

7. Goal -- A long-range objective or target stated in broad, general terms.

8. Grant Application -- Forms provided by the White House Conference to the states which must be submitted for all grants awarded under Title III, White House Conference on Handicapped Individuals Act.

9. Handicapped Individual- Any person who a) has a physical or mental impairment which substantially limits one or more of such person's major life activities; b) has a record of such an impairment; or c) is regarded as having such an impairment.

10. Issue -- A question - resolvable in two or more ways - formulated for the purpose of determining what broad policy or action should be taken to move toward a specific, goal-oriented objective.

11. Level of Participation- Includes, but not necessarily limited to: 1) delegates; 2) observers.

12. Local Forum -- A public meeting, radio program or television program involving open audience discussion related to the problems and potentials of physically and mentally handicapped individuals and suggested solutions to those problems, the results of which to be channeled into the State and/or National Conferences for review and discussion prior to final recommendations.

13. National Conference -- A meeting of official delegates from each state, members of the National Planning and Advisory Council, delegates-at-large, and observers, for the purpose of discussing the issues, developing and refining recommendations and plans for action to be made to the President and Congress, which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

14. National Planning and Advisory Council -- A Council appointed by the Secretary of Health, Education, and Welfare composed of 28 members, of whom not less than ten shall be individuals with handicaps appointed to represent all individuals with handicaps,

and five shall be parents of individuals with handicaps appointed to represent all such parents and individuals, to provide guidance and planning for the Conference.

15. Observer -- A person identified as holding some special interest in the work and objectives of the Conference who may attend the Conference, but is nonvoting and nonparticipating.

16. Program Guidelines -- A set of focused, strategically feasible principles and plans for action to provide directions for Conference activities.

17. Recommendation -- A proposal for specific action designed to implement policies and to move toward goals.

18. State -- Includes the several States, the District of Columbia, the Commonwealth of Puerto Rico, Guam, American Samoa, the Virgin Islands, and the Trust Territory of the Pacific Islands.

19. State Conference -- A formal meeting to interchange views among individuals with handicaps; members of their families; representatives of Federal, State and local governments; professional experts; and members of the general public recognized by individuals with physical or mental handicaps as having knowledge about problems affecting their lives, for the purpose of considering all issues related to the mission of the Conference, and shall be required to address specific issues as outlined by the White House Conference on Handicapped Individuals.

20. State Director of White House Conference Activities -- The person(s) appointed by the Governor to direct and coordinate White House Conference activities at the State level.

21. State Grant	-- Sum appropriated by Public Law 93-516 to be made available to each State through the Secretary of Health, Education, and Welfare, upon application of the chief executive, in order to assist in meeting the costs of that State's participation in the Conference program, including the conduct of at least one Conference within each such State.
22. White House Conference on Handicapped Individuals	-- Authorized, by Public Law 93-516, as a joint effort between the Federal Government and the States and their citizens to develop recommendations and stimulate a national assessment of problems, and solutions to such problems, facing individuals with physical or mental handicaps.
23. White House Conference Program	-- All activities at the local and State levels, related to the overall goals of the Conference, the results of which may be channeled into the National Conference for review and discussion prior to final recommendations.

ROLES AND RESPONSIBILITIES OF DELEGATES TO THE STATE CONFERENCES

State Conferences must address and propose recommendations for at least two issues (see Section F, Summaries of Awareness Papers and Issues) for each of the 25 Conference topics (see Section E, White House Conference Topics).

What is an issue?

An issue is defined by the White House Conference as:

> "A question--resolvable in two or more ways-- formulated for the purpose of determining what broad policy or action should be taken to move toward a specific, goal-oriented objective."

This is the formal definition of an issue. But what does that mean to you, as a State Conference delegate, in the generation of issues and the subsequent recommendations which will follow these issues? It will be the purpose of this paper to help you learn the format for formulating issues and resolutions because, if you do so, you will assure that your state has been adequately represented in formulating the National White House Conference agenda.

How does that work? Remember that the agenda of the National Conference is based on the issues and the resolutions submitted by the States.. When your State's Conference report is submitted to the White House Conference (within 30 days after completion of the Conference(s)), the staff members will take it apart, issue by issue, and synthesize it with all other State inputs to reduce it to the fewest common issues, plus all the unique issues that arise. The National Conference agenda will then be composed of meetings which will consider all these issues and their recommendations, and the National DELEGATES will vote on which issues and which recommendations should be addressed in the final implementation plan of the Conference. So, to assure that your State's input is adequately handled, it is extremely important that your issues and your recommendations be clearly understood, and consistent in format to the reports of issues from other States. If they are not, the information could be misunderstood, misinterpreted, and misplaced.

An issue might look like the following

> In a time of competition for scarce public funds, what innovative approaches can be taken by education administrators to assure maximum utilization of available dollars?

What makes this a good issue? It is open ended. You should be able to think of at least two good answers. You will probably be able to think of clue words that could suggest whole implementation strategies, clue words such as "monitoring systems," "voucher systems," "management training," "parent monitoring," "cost benefit studies," "legislative lobbying," etc., etc. The issue should be, in fact, a stimulus for brainstorming because it is so open ended.

And notice that the answers, which you brainstorm as clue words, are broad--they encompass many actions--they suggest systems that will produce measurable results. That also makes it a good issue, because the clue words and thoughts stimulated by the question imply broad actions that should be taken to move toward a goal-oriented action.

What is a goal-oriented action? In the above issue, that goal-oriented action is easily inferred--the goal is to secure more public funds for more services of education to handicapped individuals through increased efficiency. You can probably measure that, you know, by counting dollars and individuals served through education.

So, the issue is good because:

(a) it succinctly restates the problems (this is optional, but a good idea when possible),
(b) it obviously has more than one answer,
(c) the answers to the question have to be broad and far reaching, and
(d) the answers will result in a goal which is suggested by the issue.

What are some of the problems in formulating issues?

In some instances new issues will be formulated. A common error in developing issues is to ask a question that only has a "yes" or "no" answer. "Should the Bureau of Education for the Handicapped regulate the placement of children in special education program?" is not a good issue, because it can only be answered by "yes" or "no." That could be restated as: "Given that many children are misplaced in special education classrooms, what mechanisms can be instituted which will assure appropriate placement of each handicapped child in a special education program?"

Likewise, an issue is not good if it is too specific or narrow. A bad example: "What activities can the Handicapped Children's Early Education Program of the Bureau of Education for the Handicapped initiate that will promote further spread of curriculum for Early Education programs"? This asks a question that has definite limits, legislative and fiscal limits, only addresses one agency, and only works with a selected small target group. It would be better if the issue were phrased as: "Since the number of pre-school handicapped children served is significantly small, what actions or policies can be taken which will stimulate the growth of early intervention programs for this population?" You can see that the "good" issue will certainly provoke more innovative answers, with broader implications, than the "bad" issue.

All of these good issues also suggest goals and objectives, appropriate placement of greater numbers of children, and growth of early intervention programs. Practice formulating issues. Give yourself a problem, and then formulate an issue. You will soon find that issue making is not easy--but necessary--before you are through with your task.

But what about recommendations? The important thing to remember about recommendations is that they should, absolutely, irrevocably, and ineradicably, SUGGEST A PLAN OF ACTION IN CLEAR TERMS.

The reporting form asks States the level of agency that your recommendation will affect: Federal, state, local or private. Interpret this as the level(s) of agencies that will MOST IMMEDIATELY be affected by your recommendation. If your recommendation for stimulating growth of early childhood programs is one of intensive research at the university level, mark "private." If the recommendation is for a national information campaign, mark "federal." Or if more than one level is suggested, mark any or all that are appropriate.

The question about the disability(ies) affected is self-evident, and should need no explanation.

But then you are faced with formulating the recommendation. How do you develop a solution? As clearly, definitively, detailed and succinctly as possible. The easiest and best way to write a recommendation is to follow the reporters' code--Who, What, Why and How:

* Who should implement action toward the goal?
* What actions should be taken to reach this goal? (notice the plural of the word action)
* Why is this action superior to others and why should it be done this way? Sometimes this statement comes first.
* How should these actions be started, and by what time schedule?

As an example, assume you want to recommend that a public media campaign be used to stimulate growth of early childhood programs. You will develop a broad statement of your recommendation as the "Solution." Specific action steps to be taken would be presented as the implementation plan.

Solution: Growth of early intervention programs for handicapped children appears to be limited by general lack of knowledge about the benefits, as well as the methods of such procedures. Therefore, it is recommended that a wide-scale media campaign be mounted which will impart the information on human and cost benefits of early intervention projects to all taxpayers and attempt to influence their support of further growth. Such a campaign should depict successful projects of early childhood intervention and demonstrate the increased ability of handicapped children to cope as a result of early intervention.

Implementation Plan: The Bureau of Education for the Handicapped, through funds earmarked for Early Childhood Intervention Programs for the Handicapped, should award a contract for a public media campaign to impart information about the benefits and methods of establishing pre-school early intervention programs. Although such a program could involve state and local education information dissemination agencies, it is felt that a national effort is necessary to insure the rapid growth of programs and to reach more persons who will eventually have to decide on fiscal support.

Since funds already exist for activities like this in the Bureau of Education for the Handicapped, it is recommended that a contract for this work be awarded by January 1978 and that the campaign be mounted before the end of the 1977-78 school year. Such a campaign should utilize both print and nonprint media, with heavy saturation.

At the end of 1978, all state school systems and identifiable private service systems should be surveyed to ascertain growth of numbers of pre-school intervention programs.

That is a recommendation, broken into a "solution" and an "implementation plan." It is succinct, it gives a rationale, it answers the goal question of the issue, it locates the catalytic agency, it gives time schedules, it provides an evaluation of itself, and it suggests contents.

The importance of your role as a State delegate, in assuring that meaningful recommendations are developed as a result of the White House Conference, cannot be overemphasized. The success of the Conference depends upon you, the State delegate, and the degree to which you present meaningful solutions to the National Conference delegates for their consideration in May 1977.

WHITE HOUSE CONFERENCE TOPICS

HEALTH CONCERNS (HEC)

I. Research
II. Technology
III. Diagnosis
IV. Prevention
V. Treatment

SOCIAL CONCERNS (SOC)

I. Attitudes of the General Public Toward Handicapped Individuals

II. Psychological Adjustment of Handicapped Individuals and Their Families

III. Recreation

IV. Participation in Cultural Activities

V. Architectural Accessibility

VI. Transportation Accessibility

VII. Communications: Techniques, Systems, Devices

ECONOMIC CONCERNS (ECC)

I. Employment
II. Economic Opportunity
III. Economic Security

EDUCATIONAL CONCERNS (EDC)

I. Preschool (0-5 years)
II. School Age (5-21 years)
III. Post School (21 years plus)

SPECIAL CONCERNS (SPC)

I. Problems of the Severe Multiple Handicapped

II. Community and Residential Based Housing

III. Service Delivery Systems

IV. Civil Rights of the Handicapped

V. Unique Problems of Handicapped Minorities

VI. Unique Problems of Disabled Veterans

VII. Unique Problems of the Handicapped Aging

SUMMARIES OF AWARENESS PAPERS AND ISSUES

These Summaries were prepared by subject-matter experts to serve as one resource for discussions leading to solutions of problems facing all individuals with mental and physical handicaps. The Issues were prepared by the White House Conference, with input from consumers, organizations, other technical experts and the National Planning and Advisory Council. The Summaries and Issues were not intended to be all-inclusive, but were designed to stimulate discussion.

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HEALTH CONCERNS

Summary and Issues on

RESEARCH

Awareness Paper Prepared By

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I RESEARCH

SUMMARY OF AWARENESS PAPER

Introduction

Definition of Handicapped

It is likely that most people apply a relatively narrow definition, restricting the term to those persons grossly and obviously demonstrating a loss of function either physical (amputees, blind, deaf, for example) or mental (frank psychotics and stroke victims, for example).

A broader, more valid definition would be to consider anyone handicapped who, due to injury, disease or any other cause was unable to, or prevented from, realizing his full potential in our society. This definition is the one chosen by the author.

The Problem

How can society best and most expeditiously prevent, cure or ameliorate any and every detectable handicap? In view of current social consciousness which regarda the individual health of each citizen as his "right", now embraced by government, the government is obligated to operate so as to provide solutions for the problem.

Solutions

Research, on the basis of its accomplishments, is likely to be a major contributing factor to any solution.

Research - Definition

Research is anything which produces or develops knowledge. "Basic" or "pure" research does so for the benefit of increasing knowledge alone, regardless of its utility.

"Applied" research or "targeted" research uses available knowledge and aims at the solution of a specific problem (the target). It is likely to be of relatively immediate, practical benefit in some way to a handicapped person.

Practically, complete separation of "pure" from "applied" research is frequently impossible; the two are used interchangeably. Both have, can and will eventually likely be of some practical benefit to some handicapped humans. It should be understood there is no conflict between them whatsoever.

Poliomyelitis serves as an excellent example. The "pure" research of many, capped largely by that of Enders and Weller, provided the "basic" information which Dr. Jonas Salk, (along with many others and a segment of the pharmaceutical industry), targeted at the practical development of an effective poliomyelitis vaccine. The "applied" research aimed at this problem resulted in a solution to the problem, the target being a relatively safe, potent and effective poliomyelitis vaccine. The solution of the targeted problem, the vaccine, properly utilized, has prevented this infectious source of relatively permanent and frequently severe human handicaps. That this vaccine alone has greatly benefitted many individuals in practical economic terms, decreased the financial and emotional burden on many families and decreased the cost to the public cannot be controverted.

To the degree that "pure" research knowledge can frame future, similar specific targets on which "applied" (and additional "pure") research can effectively focus to similarly ameliorate other handicaps, such should be accomplished as rapidly as possible by every practical and possible means.

Research - Basic Concepts Relating to Research Likely to Benefit the Handicapped

1. The time-frame must be appropriate so far as the state of development of the available knowledge is concerned.

2. The quality, types and numbers of trained or readily trainable research personnel must be equally appropriate.

3. The methodology must have been developed to a sufficiently sophisticated and appropriate level that the required research necessary to develop the knowledge needed can be carried out.

4. Adequate, readily flexible funding of appropriate amounts must be available that can be mobilized promptly to head off or break bottlenecks that may hinder progress. Here, the history of poliomyelitis would indicate that available public contribution sources of substantial funding can be mobilized and effectively utilized to hit the target somewhat more flexibly and efficiently than can tax revenue; the two can - and probably should be - complementary and not merely additive in supporting unnecessarily repetitive research activities - which unfortunately may occur.

5. Interdisciplinary Research - The virtues of interdisciplinary research, especially when mobilized to promote applied

research, have been amply demonstrated in the development of the poliomyelitis vaccine and in producing many relatively safe and effective drug products developed by the pharmaceutical industry. The well-being productivity and the adjustment in society of many handicapped individuals are directly related to this kind of research.

State-of-the-Art of Research Concerned With the Handicappped

To consider this in any detail within the compass of this paper is patently impossible, likely to be distorting, and would probably lead to serious misconceptions. Generally, "basic" research in the several areas of human health has been heavily and increasingly supported by Federal funds channelled into the National Institutes of Health since the 1940's and 1950's. The funds appropriated have predominantly supported much needed basic research endeavors in the health field. Such funds have been expended not only intramurally but extramurally - and world-wide. They have supported the education and training of many competent research scientists. New institutes were created and existing institutes were enlarged as the magnitude of those many problem areas resulting in seriously handicapped individuals have been more clearly outlined and understood, largely as the result of the changing basic and applied research time-frames involved.

Perhaps as good a way as any to get a bird's eye view of these changing past time-frames leading up to the present state-of-the-art would be to superficially review the development of the National Institutes of Health, their summarized accomplishments and the pattern of their appropriations and expenditures. This would take up much more than the compass of this paper and its summary.

Perhaps the chief disappointment of their really significant performance has been that it has not produced as much of practical utility as expected by the public, in our case, the handicapped. But human expectation always outruns human performance!

One must be constrained to state that there has developed, as a result of National Institutes of Health intramural, extramural and research personnel training programs, a published and readily available data base dealing with "basic" research in many areas, out of which could and should be utilized the optimum in concepts, leads, ideas and direction for much future targeted research of likely substantial, readily-early-attainable benefit to many of the handicapped. That this should be attempted goes without saying. Unless this happens, future research support may deteriorate. This would be unsupportable, and not in the best interests of anyone, least of all the handicapped! It must be repeated - there is no conflict between basic and applied research; they merge imperceptibly into each other frequently and always complement each other eventually.

It must also be noted that substantial basic research accomplishment from the activities of many other governmental agencies at national, state and local levels, swell this basic data base resource appreciably, to say nothing of such similar swelling developed through industry and private research activities.

Research Primarily Directed to the Human Nervous System

General Commentary

Since space is restricted, that portion of the human organism, the nervous system was selected because it is most involved in health in the normal (i.e., unhandicapped) individual yet subject to many influences resulting in a great variety of serious dysfunctions (i.e., handicaps).

Again poliomyelitis was used as the prime explanatory example of how lesions to specific areas of the nervous system, in variable patterns, and from varied causative agents could produce such serious dysfunctions - and handicaps - as quadriplegia (paralysis of all four extremities) - sometimes together with respiratory paralysis in the extreme case - requiring lifetime domiciliary care (sometimes in an "iron lung") and treatment, through less severe motor paralysis of one or more extremities where variable measures of rehabilitation toward a reasonably normal existence in society could be managed.

Potential Causes of Injury to the Nervous System

Other causes than poliomyelitis virus were noted which could produce precisely similar, serious, handicaps with the same prognosis, such as infections, trauma, drugs, cancer, etc. Inherited or congenital variations of different sorts may induce similar handicaps.

Using the research and educational activities of the National Institute of Neurological and Communicative Disorders and Stroke as an example, it supports research designed to provide more information on all potentially handicap producing mechanisms acting on the nervous system. They want to learn more about causes so they can learn how to diagnose as early as possible so as to provide more effective treatment and then by education and rehabilitation how best to minimize the magnitude of the resultant handicap in the individual.

Research activities in the field of mental retardation were also considered, especially mental retardation in children and its optimum amelioration.

Recommendations:

There should be no decrease of overall research but rather at the very least and immediately, increases parallel to the inflationary pressures.

Use should be made of the basic research data base for ideas and guidelines in maximally productive target areas at which to beam "applied" multidisciplinary research efforts. It was suggested funds should be sequestered that could be readily mobilized to exploit "targeted" leads which might be developed and it was emphasized that this activity should not be at the expense of basic ongoing research.

1. One helpful concept in providing priority guidance for the direction of such "applied" efforts is an analysis of the degree of rehabilitation possible with specific types of handicaps to variable degrees. Here if one uses as a dividing line - a watershed, so to speak, to classify categorized handicaps, they can then be graphically plotted and considered on the basis of the degree to which they will require continual, domiciliary care and treatment on one side of the watershed; on the other, the degree to which they can approach complete integration into the mainstream of productive, free-living members of society with, or entirely without variable degrees of assistance from others. Estimated costs can be related to the estimated numbers which would fall into each category and aid in allocating research funds on a cost-benefit basis.

2. Parallel to the foregoing and utilizing such graphic representations and the estimated dollar values involved, the "applied" research options available at any time could be considered on a likely cost-effective basis to obtain the optimum productivity out of the research (or care, or education, or training) options available at any point in time.

The establishment of special centers for specific types of handicaps appears sensible and we strongly endorse the establishment of such centers regionally, preferably within existing hospital facilities already competent in the handicapped areas involved.

It is proposed that, either independent of the foregoing and/or ancillary thereto, a program of education and training be instituted for those handicapped capable and interested in becoming researchers, para-researchers and educators, especially in the handicapped areas. Persons who now receive lifetime domiciliary care but with unimpaired mental faculties could be trained in reviewing the data base of "pure" research for its essential information and retrieving that

information likely to provide direction to productive "applied" research more immediately beneficial to the handicapped.

Overall Summary

It is clear that the handicapped overall, have, (a) received research funding in the past, (b) they are being aided by present research, and (c) they will continue to be aided by future research.

It is equally clear that, with the volumes of published basic research readily available, appropriate utilization of it will doubtless produce pertinent ideas for more applied research that will help the handicapped sooner. This should be encouraged in every way but not at the expense of the productive basic research budget.

The potential value of Regional Centers for Research Education, Care, Training and Rehabilitation makes them pertinent and desirable. The possible relation thereto of educational and training programs to make of those potentially capable handicapped, professionally competent and productive researchers, para-researchers and educators in such centers and elsewhere, helping further to advance the productivity of research promoting the optimum welfare of the handicapped, is pointed out and it is recommended that programs such as this be developed.

ISSUES

HEC I-1 How can research and its relationship to prevention and services be better understood by the handicapped individual?

HEC I-2 How can advocates for research be developed so as to maintain the high quality of research to aid the mentally and physically handicapped?

HEC I-3 How can we include a broader population that may be interested in causes and prevention as well as treatment and rehabilitation?

HEC I-4 How can we demonstrate the benefits of research findings to professionals and other user groups?

HEC I-5 How can additional medical and scientific professionals be attracted to enter the field of birth defects and genetics?

HEC I-6 How can the public be made aware of procedures that would result in the reduction of risks for mothers and infants caused by alcohol, drug abuse, etc.?

HEC I-7 How can private and public sectors establish a comprehensive research program with emphasis on the causes of all types of handicapped conditions?

HEC I-8 From the standpoint of mental illness, how can we develop an explicit policy on which to base a nation-wide effort to disseminate research findings, and whenever appropriate, to foster their use since this need for information on mental illness is of the highest priority?

HEALTH CONCERNS

Summary and Issues on

TECHNOLOGY

Awareness Paper Prepared By

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II TECHNOLOGY

SUMMARY OF AWARENESS PAPER

Introduction

Rational discussion of technology and the handicapped demands the setting of limiting parameters. Both fields are so complex and in such a state of dynamic change that initial subdivision of the topics and exclusion of some potentially contributory but non-essential elements are required.

There are widespread differences regarding the definition of "handicap" HANDICAP has been defined by the Office for Handicapped Individuals, Department of Health Education and Welfare, in terms of the person. Thus, a HANDICAPPED PERSON is one who because of a physical or mental disability is at a disadvantage in functioning in one or more major life activities. A major life activity is a relative definition. It is assumed that such activities are those that can reasonably be expected of a non-handicapped person. Handicap, impairment, and disability are sometimes used interchangeably. There are degrees of handicapping conditions: mild, moderate and severe, based on functional limitations.

In its broadest sense, TECHNOLOGY means the systematic application of scientific or other organized knowledge to practical tasks. Its most important consequence is in forcing the division and subdivision of any such task into its component parts. Thus and only thus, can organized knowledge be brought to bear on change.

Failure to appreciate subtleties in the definitions cited and their implementation within our complex cultural and socioeconomic system has led to unsolved problems for technologists and the handicapped alike.

Scope of the Problem

There are more than seven million children and at least 28 million adults in America with physical and mental handicaps. Individuals with handicaps are all too often excluded from schools and educational programs, barred from employment or are underemployed because of archaic attitudes and laws, denied access to transportation, buildings, and housing because of architectural barriers and lack of planning, and are discriminated against by public laws which frequently exclude individuals with handicaps or fail to establish appropriate enforcement mechanisms. Not the least of the problems is the fact that the American people are simply unfamiliar with and insensitive to difficulties confronted by individuals with handicaps.

The development of new technology and the adaptation of existing technology for the handicapped have been hampered in the past in inattention to the definition of discrete, project oriented tasks, by the lack of a suitable basic science to support the managerial decision processes required, by a scarcity of people trained and educated in the application of engineering principles to the handicapped, and by the high cost of technical failures induced by non-perception of real needs. Several investigators have commented that the process of applying technology developed in other settings to the settings of health care includes not only the design of devices, but also the development of techniques for problem definition and the management of programs leading to solutions.

It has generally been assumed that the products of basic and applied research are translated into the technologies that eventually become the armamentarium of those engaged in the process of bringing about change. In the process of applying technology to the cure or containment of handicapping conditions and for the betterment of handicapped individuals, the hypothesis may not be a valid one. The problem may be that technology has only been applied partially to solutions for the handicapped. Much of the discussion about the utilization of technology for the solution of societal problems, exemplified by the problems of the handicapped, has been concerned with the needs for research, with the relative weight given "basic research" as compared with "applied research" and not with the administrative techniques used to conduct and manage that utilization. Thus, if one's primary concern is with the use of knowledge to produce change, then the order should be: 1) The use of existing knowledge to produce the desired change (i.e., to allow individuals with handicaps to live their lives independently, with dignity, and with integration into community life); 2) When existing knowledge is incomplete or insufficient, applied research to find the missing knowledge; 3) In those areas in which lack of fundamental understanding limits the scope of applied research, basic research for understanding the nature of the needs; 4) And for those areas without even an understanding of the nature of the needs, basic research without regard to any possible area of application.

In the latter sequence the most essential element in the application of the fruits of research, especially costly research, is a mechanism for transforming knowledge into the action that produces change. To be specific, in the area of technology applied to the problems of the handicapped, the most essential element is a mechanism for the transfer of technology.

Technology and the Handicapped--Generic Divisions and Frameworks of Reference

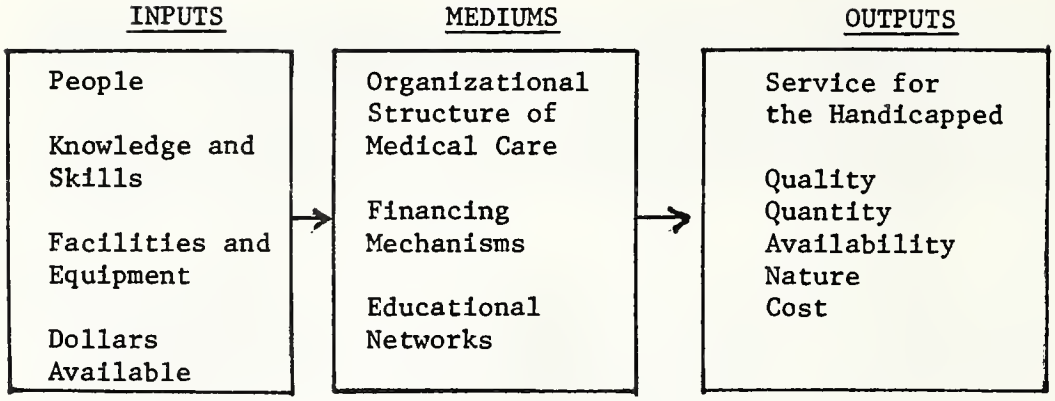
In the view of Thomas there are three levels of technology that ought to be distinguished. The first is termed "nontechnology", impossible to measure in terms of its capacity to alter either the natural course of handicapping conditions or their outcome. It is what is meant by the phrases "caring for" and "standing by". It is indispensable. It is valued highly by the providers of services for the handicapped as well as the handicapped themselves. It is sometimes called "supportive therapy".

At the next level up is a kind of technology termed "halfway technology" by Thomas. This represents the kinds of things that must be done after the fact of disability, in efforts to compensate for the incapacitating effects of certain disorders whose course one is unable to do very much about most likely because of our state of ignorance regarding the fundamental disabling processes.

The third type of technology is the kind that is so effective that it is taken for granted and attracts little public notice. This is the genuinely decisive technology of modern science. This is the really high technology of medicine based on the result of a basic understanding of disease mechanisms. When it becomes available, it is relatively inexpensive and relatively easy to deliver. Most important as regards a review of applied technology to the institution of the full rights of citizenship to the handicapped is the realization that this type of technology, the decisive technology, need not necessarily be medical at all.

Many conceptual frameworks for the description of health services delivery in this country have been proposed and discussed. Common to all is the realization that managerial and operational frameworks for the delivery system must be developed to allocate resources rationally to the overall delivery of services to the handicapped and to measure the impact of services offered. This theoretical description must have counterparts in actuality so that the impact of developed and implemented technology can be measured. Accordingly, the conceptualized system must be characterized according to its inputs, medium to be transformed and its outputs. One conceptual system is shown as follows:

Health Services Delivery--
Conceptual Framework



For each of the services or needs listed in the conceptual frameworks, evaluation is required. Regardless of the measure of output, one might imagine a "community health" function that expresses the "level of health" output in terms of the levels of inputs, such as number of doctors, number of hospitals, etc. Such a function is referred to by the economist as a production function and by the engineer as a transfer function.

The production function concepts offer three major advantages in an economic analysis of technologic intervention.

Determination of the substitution and complementary properties of the inputs to a production process; production functions enable one, in the context of community health care, to determine how the various inputs substitute for each other (nurses for doctors, paramedical people for nurses, and so on) and complement one another (doctors working in hospitals, nurses working for doctors, etc.) in the production of any level of output.

Determination of the optimum combination of categories of input resources under a given constraint: When combined with a budget constraint, the production function permits determination of the input resource mix that yields the greatest output for a given cost constraint, or, alternatively, the lower cost at which a given output can be achieved.

Determination of the returns to scale, or the multiplicative effect on output measure caused by proportionate changes in the level of inputs.

There have been many examples of the successful application of production function models to problems in industry and government.

Examples of Existing Technology Applied to Some Needs of the Handicapped

An Example of "Nontechnology"

Accidents are a prevalent cause of disabilities, especially in lower age groups.

In nonfatal accidents, rehabilitation, job retraining and job placement are vital ingredients in the total mixture of services provided. Such services are rendered by dedicated people, most effectively in service organizations as part of a system that includes medical care, often monetary assistance and specific research. As a group, the insurance industry and specific disease foundations have been able to mount the kind of broadly based centers that include the "nontechnologic" technologies.

An Example of "Halfway Technology"

The most active and best known examples of technologic intervention are in the group of applications that compensate for the effects of disorders that lead to handicapping conditions. The list of machines, instruments, devices and gadgets is endless. Almost all sciences at the boundary between technology and medicine have representative efforts in meeting some need of the handicapped. All efforts in this category are repairative, substitutive or compensatory for some function lost.

Sensory aids to the blind is a field that can be used as an illustrative case study. During the past 35 years, many efforts have been made to develop useful electronic aids for the blind. These are primarily devices that aid mobility or access to printed matter. The field has been summarized by Nye and Bliss. But no matter which of the thirty or so electronic aids that enhance the mobility of the blind works best in a specific situation, none will significantly answer the needs of the blind if building codes do not safeguard his access, if recreation facilities are not available, or if ignorance and prejudice block acceptance in jobs for which that person is now available.

A recent promising advance in the area of access to printed matter may run into similar problems. The developers* of a computerized device that scans printed pages and reads them aloud in a voice that gives appropriate stresses and pauses, have taken extraordinary pains to involve more than engineering specialties in the analysis of need and

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*Kurzweil Computer Products, Cambridge, Mass.

the various stages of development yet the cost of the unit may be prohibitive. These simple examples of technology in just one area, electronic aids to the blind, are representative of the still unmet needs of the handicapped. There are multiple similar examples that could be cited: Electro-mechanical aids for orthopedic disabilities and architectural barriers that impede access by the handicapped.

An Example of "Decisive Technology"

The most effective technologic interventions for the handicapped go almost unnoticed. They are taken for granted.

Most efforts in this category are preventive: vaccines for immunization against contracting the diseases that lead to handicapping conditions or avoidance of some environmental or pharmacologic toxin that affects fetal or immediate prenatal well-being.

The most spectacular recent example was the development of the polio vaccine. It is important to note that the final realization of that success was based on a long history of seemingly unrelated scientific discoveries in techniques of cell culture and viral immunology that enabled Sabin and Salk to complete the attack on the once dreaded disease, poliomyelitis.

Recommendations

It is evident that the requirements for successful technologic intervention are:

More efficient organization at a national level.

Planning based on better demographic and sociologic data.

Specialized manpower of the type now being termed "clinical engineers" who can join the team of specialists working for and with the handicapped.

Coordinated and stable funding of technologic research, intervention and assessment based on national rather than parochial objectives.

It should also be evident that neither the private nor the public sectors alone can marshal the spectrum of effort required for the successful intervention of technology for the handicapped. Each has areas of wherewithal to contribute.

ISSUES

HEC II-1 What steps should be taken to facilitate the transfer of technology so that handicapped persons receive the benefits of technology as rapidly as possible?

HEC II-2 How can the benefits of new technology be published and disseminated to handicapped persons?

HEC II-3 How should we address the proliferation of technology and develop a meaningful response to the problem in order to benefit the handicapped?

HEC II-4 How can the handicapped person be protected from charlatan technology? (regulation of products and services)

HEC II-5 How can the interests of handicapped persons across the country be better served by improved communications including telecommunications (audio-visual) in the health field?

HEC II-6 How can a data bank in the field of technology be created to serve all levels of government, industry and consumer groups?

HEC II-7 How can a more efficient organization be created at the National level to bring together all efforts required for the successful intervention of technology for the handicapped?

HEC II-8 How can we obtain better data for use in planning for technological applications?

HEC II-9 How can specialized manpower, now being termed, "clinical engineers" join with handicapped individuals using technology and modern engineering?

HEC II-10 How can we insure that technology does not replace human relationships?

HEC II-11 How can we address the many legal and ethical questions which have arisen in our society due to applications of technology (For example, the right to privacy in data collection)?

HEALTH CONCERNS

Summary and Issues on

DIAGNOSIS

Awareness Paper Prepared By

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III DIAGNOSIS

SUMMARY OF AWARENESS PAPER

The identification and assessment of individuals with handicaps is presently being carried out on an increasingly large scale. Recent legislation has been to increase such activities under Federal sponsorship to include younger children with emphasis on the disadvantaged. This underlying concept of early identification will prevent later difficulties, particularly those of an emotional nature.

Title XIV of the Social Security Act mandates "early and periodic screening, diagnosis, and treatment" for physical and mental defects, and pilot programs for carrying out such activities are now in place. Regional and local community programs are also involved in seeing children and adults for comparable diagnosis, yet in a somewhat less systematic way.

The concept of "handicapping condition" has been broadened from how it has been used in the past. Now it is acceptable to say that a handicapping condition" is any condition likely to prevent a person from achieving optimal growth and development. An earlier view was that damage of a physical nature would cause limitations in an individual's development. It was also believed that mental retardation was caused by physical damage to the nervous system which led to lower levels of development.

Newer beliefs are that both social and emotional experiences interact with the physical aspects and lead to effects that may limit the development of the individual. New categories of handicapping conditions have therefore arisen and professionals seek to identify those individuals who will function at less than normal development because of various inborn and environmental deficiencies.

The goals of this paper are to describe the present "state of the art" in terms of the concepts underlying the activities of screening and diagnosis, so as to formulate the issues and problems that such approaches have brought about. Possible directions for dealing with such issues are then suggested.

Screening and assessment are considered in relation to three aspects. The first is the type of questions asked and the kind of answers generated by this assessment procedure. This aspect is referred to as the Product of the screening-assessment. A second aspect is the way this data is generated, how questions are asked and what the questions and answers mean to the people involved; this aspect is call the Process. A third aspect is the System by which such questions and answers are generated involving people.

The screening assessment programs for handicapped individuals should be considered as a system, and its parts are related to each other so as to follow a pattern that will go in a particular schedule across time and a number of places. This pattern must have a clearly defined purpose and activities so as to achieve such a purpose. There is also a need to monitor this systems activities. In this manner, one may measure the degree to which the system is meeting its goals and will be able to adapt to unexpected changes that may occur.

The first question to be asked about any system is, what is the goal? The goal of this system is to diagnose individuals accurately, reliably, and at as low a cost as possible. Costs should not be measured only in terms of expenditures, for failure to identify an individual with a treatable condition while less advanced and, therefore, more amenable to treatment would cost a very high price in terms of opportunities lost. Therefore, early identification is one way of lowering the cost. The goal is, therefore, to discover defects for eventual remediation as soon as possible.

Yet to measure the success of such a program would be determined by the degree to which those needing help are identified. Again, the criteria for the selection of tests for such programs include consistency on repeated measurement, and accuracy, in the proper categorization. Present efforts in test development have been directed to accuracy or validity of prediction by correlation with existing general intelligence scales. Professional effort has been devoted to insure that most children needing help are identified and not too many are missed. Yet, the accuracy with which children are identified does not rest merely with a test, for accuracy will vary with the decision as to the goals of any particular system. The incidence of difficulty may be expected to be greater than the normally expected distribution if one is sampling in a population at high risk. Are there any absolute criteria that can be used that can be related to norms for any area of concern?

When dealing with applications of nationally derived norms to any specific population, an additional problem arises due to the racial and ethnic diversity and there is often an expressed need for socio-culturally appropriate norms for differing populations.

The second question addressed in the analysis of the existing system is where and when do things happen? The general principle of this system is to start with the entire population and gradually narrow the numbers with which one deals. This first stage is the screening, and subsequent stages are considered assessment, in which the difference is a matter of degree rather than any significant difference in the kind of activity. In rural areas, those identified as in need would go to the second stage for diagnosis and this type diagnosis would continue until the individual becomes greatly separated from the usual site in which he functions, for it is usually in a larger center where more highly

trained staff may be found. In this linear process each stage serves to identify only those who need to move the next stage. Because of this, the efforts put forward for the assessment process are extremely costly and only a very small number enter into treatment as a result of this undertaking.

With problems of the present system, a major problem exists in relation to the stated goal of accurate diagnosis of individuals and their conditions. A major issue is with the linearity of the system as it has been traditionally conceived. Costs are high when the goal is the accurate diagnosis of handicapping conditions without the development of treatment plans. Diagnosis is traditionally regarded as separate from treatment and it is important to suggest that treatment be instituted at each stage of diagnosis.

The outcome of diagnosis must address certain questions, and the first one should be, is there disease? The answer is based upon the ideas that there are certain findings that will help establish a "yes" or "no" decision as to the presence of disease. The presence of any abnormality helps the diagnostician to decide that there is disease present. This model of assessment is clearly useful in medicine, and a set of decisions as to the treatment can flow from this.

Over the years, various categories of "disease" have arisen to prominency. These include concepts of social-emotional difficulties as well as the more obvious physical difficulties, and the criteria for diagnosing various types of mental illness are spelled out in diagnostic manuals. A disease must apparently be present for treatment to be provided and therefore, we must screen populations before treating them.

Another basis for answering the question of whether disease is present, is a statistical one in which the disease may be a matter of degree.

Where is the disease? This would be the next question asked in this medical diagnostic model. With that, one looks for the particular organ by reviewing the various systems of the body to determine if there is an abnormality. Tests are comparably carried out for developmental difficulties to determine the site of difficulty and these assessment procedures are generally made up of several different tests. The data generated as to the areas of concern, are to be used for decision making and there are various modes of treatment for different sorts of problems since the area of difficulty has been defined. So far, no treatment has been instituted. Decisions, as to the presence of disease, are based upon the professionals trained to access the various areas of function. There is frequent overlap, but a composite picture requires a team of people each contributing from their own particular vantage point.

In a similar fashion, one looks for the cause of the patient's condition. Could the schizophrenia be due to the confusing messages provided by the mother or the biochemical constitution of the patient? What is the cause for the child having difficulty in learning? Could it be his poor pre-natal care and small weight at birth? The idea of this approach is that there may be a single cause that may be removed with the recovery of the individual. This approach works well with medical illness. The illness a person displays is the result of the ability of the person to counteract the impact of an agent foreign to the body. When adapted to developmental problems, categories have similarly arisen in terms of possible causes just as had previously arisen in terms of the site of the problem. Yet developmental problems cannot be easily or usefully attributed to a single cause.

Indeed, there are many classical labels commonly used to identify disabilities, and there are considerable variations between the different states. However, it is important to recall that the goal in diagnosis is to produce a plan for treatment. A plan for treatment for medical illness does arise with the use of these questions. Unfortunately, labels lead nowhere or to treatments that compound the problem. Society often defines what is exceptional, and labeling requires behavior appropriate to the label. Such labels may provide a diagnostician with an excuse for his or her failure when confronted with an individual who has a label.

The product of the screening-assessment activities is to develop data for decision making, and the decisions thus far seem to be mainly administrative. They are often vague and do not lead to appropriate treatment and furthermore they serve to bias observers in a negative way. Again, to call a child retarded reduces our attentiveness to changes in his development, or to say he is visually impaired makes us unappreciative of how well he can see, and how he could be helped to see better.

There has been a fragmentation of the individual into categories that do not relate to real needs. There has also been a fragmentation between various professions who deal with different functions as well as between the professional staff and those who work with the individual on a day to day basis. The process of assessment is considered to be one of non-interaction, for both the examiner and person being examined are somehow disembodied and do not participate as people in the testing. In their concern for consistency and stability, the testers no longer replicate the process of development that they wish to predict; that process of learning requires an interaction between the individuals. The process of diagnosis removes the handicapped individual from parent and teacher to whom he will eventually return. These primary participants do not generally observe the interaction with the examiner

and it is assumed that some absolute activity goes on that the parent and teacher might affect. Yet, it is they who truly affect a child's performance. It is their awareness of that fact and how they may change the way they do things that is an important message to be communicated. Additionally, referral forms generally ask parents and teachers what is wrong with the individual, what they have been concerned about. The impact of such questions infers that they, the parents, have done wrong. A helpful change is to couch the screening questionnaire in positive terms of what the child can do successfully.

It is suggested that a primary goal of the diagnostic process be to involve in as direct way as possible those who will carry out the treatment. Those who carry out the treatment should be the people who are ordinarily closely and directly involved in the life of the handicapped individual.

There is a need to make the examination a process that seeks not only to predict but also to enhance. The interaction between the examiner and individual may be a replica of the process of development. There must be an opportunity to change conditions, and it is the self-conscious awareness of what works that may become part of the product of the assessment. The data sought is no longer only a score of what the individual does. The data sought is what one does to make it possible for the individual to succeed. The data is of the process. The product now includes awareness of the process.

The effective communication of what works to those who will carry out the change in conditions must be an intrinsic part in the process of diagnosis. The removal of the individual from his or her natural environment for the purpose of diagnosis, is contrary to the need for reintegration, and assessment can no longer be divorced from treatment. Feedback must be provided to those individuals, at every stage of diagnosis, who will carry out treatment.

These passive observers must see themselves as an integral part of the assessment process. The goal is to increase the degree to which the primary participants become more competent and confident in the problem solving assessment of a situation. The questions asked convey a message to those answering them. This process of assessment may be considered as an in-service training program for child, parent and teacher. The product of such training is a greater awareness of what are their concerns, what has gone well, what works and what are their goals and what would one like to accomplish now.

The concept of "diagnosis" has generally been that of labeling or otherwise categorizing the individual with handicaps. Many labels are in use. Such categories have undoubted administrative value but are

less likely to be helpful to the individual with whom one is concerned at any one time. A non-categorical approach that deals with individuals who have handicaps on the basis of real-life terms.

The identification of those having problems and the specific areas of concern is made by those who have closest daily contact. It is their statement that a problem exists that is the meaningful one. Norms have been established for the various functional areas. Not all people are equally competent in all areas. Conversely, no one is equally incompetent in all areas.

The diagnostician is by definition limited in interaction. The primary participants in the situation for a child for example, would be those who have ongoing relationships with the child. These would be the teacher, parents and the child in order of increasing participation. In the case of an adult with handicap, the primary participants would be the therapist who serves as the consultant. The issue is merely to emphasize the relatively limited role of the professional in the total life of the handicapped individual.

The consultant diagnostician must involve in the process of decision making these primary participants, for it is they who help define the objectives to be met and strategies to be used in meeting these objectives. The diagnostic personnel serve to provide technical expertise but the individuals remain ultimately responsible and the objective is to enhance existing competence by recognizing it. The specific concerns and the specific strategies for solving one's problems are but a model that may be applied to other concerns. The assessment process is thus a consultative relationship that is designed as an educational experience for those involved.

An interaction between a diagnostician and primary participant consists of the exploration of a plan, an interim in which the plan is carried out and follow-up to complete the process. Assessment goes on of the degree to which previous goals were met and re-exploration goes on of the planning questions but now at a greater degree of awareness.

A collection of strategies should be available as to how these individuals have dealt with interpersonal relationships effectively. The consultant will be able to increase his/her repertoire of suggestions to subsequent patients with similar problems. It is suggested that an automated record of such creative problems solving techniques would be a valuable national resource. It is well to consider that we are all handicapped to varying degrees. The ability to compensate or otherwise solve our problems so that we are not disabled is the goal of all. It may well be those who are identified as handicapped have found solutions that those of us not so officially designated may find helpful.

The product of assessment should be a plan for treatment based upon the input of those who observe the individual on the most frequent basis. They are considered the primary participants in the assessment as well as treatment process. The role of the diagnostician is that of a consultant regardless of professional background. It is expected that the more highly skilled professional would work with those participants who are most in need of education and training. However, the role at every level is to increase the awareness by the primary participants of the process of problem solving. Generalization may then go on of the process by which a specific problem is solved to other settings independently of the consultant. The data generated in the assessment at each stage is true only for that time and place. At each interaction, concerns and objectives will differ. What seems to work may also change from time to time.

What remains the same is the process of assessment - the questions one asks in this planning process.

What increases, includes the awareness of the steps in that planning process, the clarity with which concerns are specified, the repertoire of options as to what might work, the ability to consider a number of options as to goals, the specificity with which they are set as well as the degree to which this activity is done independently of the consultant.

ISSUES

HEC III-1 How can diagnostic teams be made available to all citizens for all handicapping conditions?

HEC III-2 How can early diagnosis be guaranteed throughout the life of all individuals so as to minimize the risk of a physical or mental difficulty becoming compounded?

HEC III-3 What is the most effective and efficient way to insure early identification of handicapping conditions?

HEC III-4 How can labeling or other categorization of the handicapped individual be avoided, even though such categories may have some administrative value for planning and funding?

HEC III-5 How can a public awareness program help to develop a better understanding of the need to provide diagnostic services?

HEC III-6 How can we better understand the need to provide diagnostic services for all types and degrees of handicaps?

HEC III-7 How should the public and private sectors collaborate in a joint effort to help parents in knowing where to obtain professional diagnostic advice?

HEC III-8 How can we assure that effective treatment will follow diagnosis?

HEALTH CONCERNS

Summary and Issues on

PREVENTION

Awareness Paper Prepared By

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IV PREVENTION

SUMMARY OF AWARENESS PAPER

This paper will enumerate major diseases contributing to disability in the United States and will discuss those factors which can be brought to play in implementing a prevention strategy.

Prevention is the logical consequence of the ethical goal of minimizing the numbers of persons becoming diseased and disabled. The only way to minimize these adverse events is to prevent the occurrence of damaging exchanges or exposures in the first place, or to seek to minimize damage when exposure cannot be controlled.

There are two forms of prevention. One is primary prevention, for example, avoiding the occurrence of the disease or cessation or abatement of hazardous exposures. The other is secondary prevention, which is the early detection and prompt treatment to avoid progression of the disease and resultant disability.

Specifically, how can accessible information be utilized to reduce the burdens of disease and disability? The discussion is directed toward the recognition of the causative agent, identification of those at risk, recommendations for reduction of mechanisms, and, finally, strategies needed to be developed so that goals can be set and progress measured.

A preventive ethic must permeate other objectives and goals. Underlying environmental and social determinants of major human disease and resulting handicaps need to be identified. Automobile-related injury, tobacco, alcohol and other drug damage, the perils of the workplace, environmental and occupational pollution--all of these threats inflict disease and disability on society. Several options for reducing disease and disability are to: (1) Create strategies to minimize exposure of the public to hazards (physical, chemical, biological, etc.) so as to reduce the rates of hazardous exchanges, (2) create strategies to protect the public against disease and disability in situations where exchanges occur, and where such techniques are feasible (flouridation, seat belts, etc.) and (3) create strategies to organize detection and treatment resources in the community so as to minimize damage that does occur.

The common causes of physical disability among the young are cerebral palsy, spinal cord lesions, and fractures; in the middle aged, rheumatoid arthritis, multiple sclerosis, and degenerative neuromuscular disease; in the elderly, there are osteoarthritis, strokes, amputations of the lower limbs, and cardiorespiratory diseases. Through primary prevention

a number of these conditions can be prevented. Through secondary prevention a reduction in the degree of resulting disability can be accomplished.

There is evidence that in the developed countries, physical disability is present in about 3-6 percent of the population. Thus, in the United States there may be as many as 10 million people with some form of physical disability. Of these, some require minor support, others need considerable support, and some are very severely handicapped. The age incidence of disability is significant; whereas the incidence of physical disability is less than 5 percent in the young and middle age, it is about 25 percent in the elderly population. Indeed, about five-sixths of the disabled population is of the pensionable age.

A larger number of people now live and survive into older groups. As a result, the chief health problems confronting the United States are the chronic and degenerative diseases, such as cancer, cardiovascular and renal diseases, arthritis and mental changes associated with the aging. The etiology and pathogenic mechanisms of many diseases have been elucidated through clinical and epidemiological studies. Survival of all age groups with chronic diseases is increasing through improved treatment modalities. Children born with spina bifida cystica or myelomeningocele are now surviving in increasing numbers as a result of modern developments in surgical treatment of the newborn. Whereas some years ago there was about an almost 100 percent mortality, there is now 60 percent chance of survival to the age of 5 and beyond.

Cardiovascular disease accounts for 50 percent of the deaths in the United States. A large percentage is premature. There is evidence for environmental factors in about 80 percent of these cases. Nutritional factors, cigarette smoking, and occupational exposures play a role in accelerating cardiovascular disease. Cancer accounts for about 17 percent of all deaths in the United States, nearly all of which can be considered premature.

Environmental factors, including cigarette smoking, diet, occupational exposure to carcinogens, and other personal or hygienic factors are related to about 80 percent of all cases. Homicides, suicides, and accidents account for 8 percent of deaths and a high percent of disability that occurs primarily in younger age groups. Essentially all injury deaths involve environmental agents or conditions. Thus, a large number of premature deaths are related to environmental factors, and preventive measures directed towards control of these factors offers the greatest potential for improvements not only in terms of mortality, but in terms of disease, injury, and disability. There are over 14,000 occupational injuries in this country per year,

and over 100,000 deaths per year that are associated with occupational factors. Prevention of these problems is conceptually simple, that is, to ascertain the health effects along with the measures of exposure, determine the conditions or exposures related to excess disease and reduce or eliminate these conditions.

Mortality from cancer represents approximately 17 percent of the deaths in the U.S. annually. Data from epidemiology, migrant studies in occupational health indicate that 80 percent of human cancers are due to environmental factors, most of which are man-made and consequently can be prevented. Incidence of mortality from various types of cancer stem primarily from two factors--the use of tobacco products, especially cigarette smoking, and personal dietary habits. For the former, primary prevention strategies include programs of public information aimed at stopping or not beginning the habit and reducing the tar content of cigarettes. For the second factor, research studies indicate that macronutrients of the western style diet contribute to cancer of the bowel, breast, prostate, pancreas, and kidneys. A high intake of dietary fat and consumption of fats containing nitrate are two known risk factors. Cancers caused by occupational exposures is in many cases ill-defined but represents only a small fraction of the burden of cancer mortality in the United States.

A variety of diseases exists which develop slowly with advancing age and involve progressive damage and structual disorganization of the affected organ. One example is arteriosclerosis, the etiology of which is obscure but for which two environmental factors are known--cigarette smoking and high dietary cholesterol. An intensive effort is now being made to discover other environmental factors, for example, mineral composition in drinking water, metals in occupational exposure to chemicals. Other diseases in which environmental factors have been identified or implicated include cirrhosis (alcoholism), chronic bronchitis and emphysema (cigarette smoking, air pollution), chronic diseases of the kidney, (drug ingestion and trace metals), endocrine organs (nutritional factors), nervous system (trace elements), musculoskeletal system (repetitive trauma), and hematopoietic system (drugs and chemicals). Research into the causative biomedical factors related to degenerative diseases is hampered by the chronic nature of the problem and the tendency to focus on more immediate problems. Long-term efforts are required to elucidate the role of the environment in the etiology of chronic disease and disability and the implementation of research and control programs for their prevention.

In the United States injuries are the leading cause of death from age one until the beginning of the fifth decade of life. Because the median age of persons dying of injuries is only 38 years, these

deaths greatly reduce productive years of life. The number of working years age 18-65 lost because of injury deaths approximates the total for cancer and heart disease combined. In 1970 injury deaths, excluding military and non-military injury deaths outside the U.S., totaled 160,000 including 23,000 suicides and 17,000 homicides. The largest number of injury deaths were associated with motor vehicles (55,000), firearms (25,000), falls (17,000), poisoning (12,000), drowning (8,000), non-vehicle or fires and burns (7,000). Among the aged, injuries are primarily due to non-motor vehicle accidents such as falls and fires. During the most productive years of life and in many countries during childhood as well, motor vehicle fatalities comprise the largest category of injury deaths. Increases in the number and use of motor vehicles have been accompanied by dramatic increases in the number of deaths and injuries, especially among teenagers and younger adults. Most injuries can be prevented or reduced in their severity; they are not chance or random events but predictable results with specific combinations of human and environmental factors.

Homicide and suicide are among the leading causes of death and disability in the United States. Within the 15-24 age group they are the second and third leading causes, exceeded only by accidents. Approximately two thirds of all murder victims are killed with guns, and the proportion killed in this way increased steadily throughout the sixties. The number of handguns in the United States today is reported to be 40 million, raising by 2.5 million each year. The cost of health care and rehabilitation for victims of shootings and the cost of law enforcement to protect against these shootings is obviously very high.

Prevention of health problems associated with the use or abuse of substances such as food, tobacco, alcohol, and narcotics and other drugs is particularly difficult because of the absence of agreement on certain criteria for distinguishing use from abuse. The abuse of food is defined in terms of consequences of obesity, for example, cardiovascular and renal disease, diabetes, and injury from falls. About 80 million Americans are 20 pounds or more overweight and the prevalence of obesity has increased as exercise has been divorced from most occupations, household, and transportation activities.

Alcohol prevalence surveys estimate there are 6.5 million heavy escape drinkers. A number of disorders are related to alcohol abuse, including vitamin deficiences, gastro-intestinal and metabolic diseases, neurological and psychiatric disorders, cardiovascular and hematological conditions.

The increase in the use of tobacco can be correlated with the 3.5 percent annual rise in cigarette production, reflecting both population growth and increase in young smokers, particularly teenage girls. There is stong evidence for the association of smoking with cardiovascular disease, cancer, chronic pulmonary disease, and peptic ulcers. Current data indicate that 600,000 to 800,000 persons are addicted to narcotics which can lead to endocarditis, hepatitis, and cardiac failure.

There are widespread deficiencies in prevention program development and implementation. These deficiencies stem from several sources: (1) inadequate emphasis given to prevention in federal legislation; (2) lack of priority given to prevention training programs; (3) inadequacies in content and teaching methods related to prevention; (4) inadequacies in the organization and management of settings for learning prevention; (5) insufficient funds to support research and control activities. Federal legislation has a powerful impact in education and practice. Although prevention has been given prominence in some legislation such as that relating to the environment, to health maintenance organizations, early periodic screening of children, and the recently enacted National Health Planning and Resources Development Act, which identified prevention as one of its top priorities, other crucial proposals for legislation incorporating prevention strategies have been ignored. One primary example is the delay in passage of a Toxic Substances Act, which would ultimately reduce the presence of mutagenic, carcinogenic, and teratogenic chemicals in the environment.

Recent history indicates that it takes from 5 to 25 years for a technique, once developed, to become widely accepted in the health care delivery system. This lag between development and general use should be reduced by more prompt and systematic evaluation, and the new procedures should be followed if they are found meritorious. Demonstration programs should be developed which would transfer technology to the medical profession and the public in a more rapid fashion.

Scientific and technological advances have provided considerations for secondary prevention programs. Technical means have been developed for surveillance of conditions important to health and the identification of deviations that often evolve into disease. Procedures for detecting abnormal conditions need to be evaluated to determine the extent of their usefulness and a major effort made to incorporate these procedures and knowledge into physical and behavioral risk factors which become an integral part of personal health services. A new thrust toward health maintenance based on finding and controlling the conditions that lead to the disease and disability should constitute modern preventive action. This approach should take the form of a minimum

set of physical and counseling procedures designed specifically for various age and sex groups. Rather than a general annual checkup, it would be possible to outline the precise minimum steps that should be taken at certain critical periods of human development, namely, pregnancy, infancy, school, and pre-puberty, entry into adult life, every five years during early and middle ages and every two years thereafter. This minimum set of preventive medical services could be made available to all persons, with special additional procedures included for individuals known to be at high risk for particular disabling conditions.

Prevention of fetal and neonatal morbidity is carried out by family planning and counseling of the pregnant mother, monitoring the mother and intrauterine monitoring of the fetus and intensive care of neonatal births. Research should be directed toward elucidating the natural history of diseases. Such knowledge indicates the most vulnerable points of disease development, where intervention might be effective. Examining the present state of medical science in relation to the natural history of disease will indicate the potential as well as directions toward establishing more effective intervention.

Major reductions cannot be expected from curative health services alone. Future progress will have to come largely from alterations in the environment and life style. Modern disease and disability prevention is not confined to doing things for, and to, people, for example, ensuring them of safe food and water and immunizing them against infectious diseases. Increasingly, knowledge about personal health risks to individuals and society and how one can alter environments and change attitudes and actions to insure healthful living are required. Modifications of behavior and changes in environment are the prime areas for improvement.

Chronic diseases appear to be more dependent on personal behavior. Thus, an important means of preventing current health problems is through influencing daily habits of people. Examples include counseling for modification of diet to reduce intake of calories, saturated fat, cessation of smoking, reductions in alcohol consumption, exercise to combat physical inactivity, accident prevention, control of genetic disorders, and family planning.

Education should be initiated in early childhood and continued throughout life, changing with the changing needs of the individual, keeping pace with newer health information and practices.

The application of prevention into attitudes, knowledges, and practice of health care providers is also required. Medical education still emphasizes and reinforces an orientation toward diagnosis and treatment of disease brought by patients to medical centers and clinics

where medicine is practiced. Medical education teaches physicians to effectively deal with manifestations of disease, and there is a preoccupation with that aspect of medicine which leaves little encouragement for preventive approaches. The sense of responsibility for health maintenance must be sufficiently cultivated. A major task, then, in the area of prevention will be to orient more rapidly those attitudes and practices of physicians and other health care providers through professional education.

In conclusion, prevention is the systematic advancement of knowledge of the causative factors in disease and the reduction of disability through the application of that knowledge.

Research and control programs will have to be realigned to make a commitment with other sectors of the community to promote prevention at all levels. Major prevention policies will have to be brought into consonance with such things as agricultural subsidies, food assistance, product advertising, pollution control, highway safety, housing and law enforcement.

The preventive aspects of this Conference should result in the development of a set of priorities for restructuring existing situations to maximize protection to the public from disease and disability. The strategies should create policies and obligations to replace present situations where the latter permits specific conditions, commodities, services, products, activities or practices to pose a direct threat or hazard.

The primary objective in all considerations should be a full span of life, free from illness, injury and impairment and an opportunity for each person to realize his full capacity for physical and intellectual growth.

It is incumbent on this Conference to perpetuate the impact of prevention on health status not as an alternative to treatment but as a part of a well conceived program for improved quality of life for the Nation. A main thrust of this aspect of the Conference should be the development of national and local strategies for a new public entitlement--the right to full and equal protection for all persons against preventable disease and disability.

ISSUES

HEC IV-1 How can a higher priority in the allocation of national and state health resources be given to prevention?

HEC IV-2 In the fields of maternal and infant care, how can we direct attention to environmental conditions and other high risk factors which can cause developmental disabilities?

HEC IV-3 What can be done to generate greater public concern for genetic counseling in the prevention of birth defects due to genetic (inherited) disorders?

HEC IV-4 How can we demonstrate the benefits of preventing accidents and diseases that cause handicapping conditions?

HEC IV-5 How can more emphasis be given in the nation's medical and other professional schools to the teaching of courses on prevention along with the more traditional courses on diagnosis and treatment?

HEC IV-6 What should be done in the field of Federal and State legislation so that the prevention of handicapping conditions is addressed in a comprehensive manner and that adequate funding is provided?

HEC IV-7 What studies and pilot programs are needed to make the public aware of safety, occupational, transportation and environmental hazards; alcohol, drug abuse, and control of toxic substances, effects of faulty nutrition, carelessness in work habits, personal behavior alterations, etc., which will tend to reduce the incidence of disabilities?

HEC IV-8 How can people become aware of the need to educate themselves on healthful life styles?

HEC IV-9 What research efforts are needed in the field of prevention to increase our understanding of the causative influences of various hazards and their combined effects in for example, cross hazard impact studies (asbestos and smoking), long-term exposure studies, specific etiologies of disabilities and disabling diseases, preventive methodologies and strategies?

HEC IV-10 How can a public awareness program help to increase our understanding of the benefits of education, emergency medical services, shock trauma facilities, prompt evacuation of injured persons from the scene of highway accidents to insure that injuries will not become disabling to the individual?

HEALTH CONCERNS

Summary and Issues on

TREATMENT

Awareness Paper Prepared By

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V TREATMENT

SUMMARY OF AWARENESS PAPER

The following is a summary of the awareness paper on Treatment. Treatment is a complex topic which includes treatment of the physically handicapped, the mentally retarded and the mentally ill. It also includes treatment of persons of all age groups from infancy to old age, the handicapped veteran and others receiving rehabilitation engineering services, dental treatment for handicapped persons, treatment and other services provided by the Maternal and Child Health Program and the Crippled Children's Program of the Department of Health Education and Welfare.

The summary includes five parts as follows:

Part I - Physically Handicapped Children; Their Problems and Current Needs by Chester A. Swinyard, M.D., Children's Hospital at Stanford, Palo Alto, California.

Part II - Treatment and Habilitation Challenges in Mental Retardation by Frank J. Menolascino, M.D., Professor of Psychiatry and Pediatrics, University of Nebraska Medical Center, Omaha, Nebraska.

Part III - Treatment of the Mentally Handicapped. Contributed by the National Institute of Mental Health, Rockville, Maryland.

Part IV - Includes section on Vision, Dental Treatment and contribution on Rehabilitation Engineering by Anthony Staros, the Veterans Administration, Richard LeClair, Department of Health Education and Welfare and Gustav Rubin, M.D., Consultant in Orthopedics, New York City, N.Y.

Part V - Contributed by the Maternal and Child Health Program and the Crippled Children's Program Department of Health, Education and Welfare, Rockville, Maryland.

SUMMARY ON TREATMENT

PART I

TREATMENT OF THE PHYSICALLY HANDICAPPED

Objectives of this paper:

In 1972 the Department of Health, Education and Welfare estimated that more than 25,000,000 non-institutionalized citizens of our country were limited in activity to some degree by chronic disease or impairment. Our objective is to provide a perspective of the diversity and magnitude of the services required by more than 9 million handicapped persons in this nation who are under 21 years of age. In this group are nearly 2 million children under 17 years of age who have a chronic condition which provides some degree of activity limitation. The most common causes of death in children under 14 years of age are congenital malformations, accidents, malignant neoplasms, and pneumonia. Since many of the accidents are related to congenital physical disability, the question of human prenatal development is pertinent to vital questions related to the handicapped newborn and to public responsibility for these conditions.

Handicapped consumers or professionals should feel free to take issue with or support any concept he wishes according to his own experience and dictates. Everyone will recognize that the subjects of position papers are not necessarily separate entities, since degrees of mental retardation and emotional problems are frequent in a large percentage of those with physical handicap.

Each of us attempts to look objectively at the entire field of physical handicap, but as a consumer, we are most familiar with the problems and available service for our own handicap, for which we are both advocates and experts. It would be unfortunate if groups of representatives of different handicapping conditons contended with each other for improved services; however, it is exceedingly difficult to establish the quantity of research or service funds available for specific types of handicap from federal, state, county, community, or private agencies. But, even if an approximate figure were derived, even greater difficulty would arise if one were to attempt comparison of the effort in behalf of one condition versus another and make a value judgment on shift of funds from one category to another. For these reasons, the conferees will need to act as representatives of handicapped persons as a unity and examine the financial support available from all sources with reference to the magnitude of the public health problem we represent.

A concept of physical handicap:

In this context physical handicap is considered to be an aberation of physical development or function occurring prenatally or acquired postnatally, which limits physical function and/or generates within the affected person feelings of inadequacy and anxiety with resultant impairment of intersocial relationships. When viewed in this context one becomes concerned with the entire gamut of physical handicaps ranging from a missing single digit to traumatic quadriparesis, and for normally or abnormally proportioned bodies of those 3-feet dwarfs or 8-feet giants whose extremes of growth failure or excess generate vocational and psycho-social problems. It also includes the abnormally proportioned child with Down's Syndrome, even though physical independence in activities of daily living might be possible. In other words, our concern extends beyond the boundaries of functional aspects of limb developmental failure or postnatal accidental loss and is concerned with independence in living, the limitations on mobility imposed by society through architectural barriers, and is concerned with attitudes of others toward the handicapped person which distort what should be equality on social interchange but which actually leads to public discrimination in education, employment, and environmental exploration.

Magnitude of the problem:

Although we have made some general remarks about the magnitude of the problem, it is difficult to obtain accurate figures on the frequency of physical handicap because the varieties are so numerous. For example, Dr. McKusick's most recent catalogue of human diseases transmitted by Mendelian mechanisms of inheritance references nearly 2,400 separate types, most of which are accompanied by some aberration of physical development. The second category of prenatally determined physical handicap are those which reveal variable genetic influence which is described as multi-factorial or polygenic association. This group includes many varieties including spina bifida and certain types of limb deformity. In a third category there are from 3,000 - 5,000 newborns annually with physical dysproportion resulting from chromosomal defects. In a fourth category one could place about 88% of the cerebral palsy patients whose brain injury resulted from a variety of prenatal causes in contrast to the 12% or 13% whose brain injury occurs after birth. In postnatal life accidents are an important cause of physical handicap during the first 20 years of life.

The enormous numbers of newborns who enter this world with a physical handicap plus additional thousands who acquire this distinction through accident or disease occurring after birth provoke contemplation about the biological and environmental hazards which affect all of us during prenatal and postnatal life. Such contemplation is relevant to

this conference agenda since it points up the developmental fallibility of humankind as a species and provides the logic for allocating responsibility for the handicapping conditions, which comprise the central theme of the White House Conference.

Man's concept of human superiority enables him to understand that a high percentage of developing bird or fish eggs might be lost as a casualty of the environment in which they develop. He understands that, among eight eggs in a nest or 1,000,000 developing salmon eggs in a stream, the environmental toll might result in only one or two young developing into an adult bird or fish; but the biological laws of nature have not been repealed for the human species, and the environmental prenatal death and defect toll is very real.

The relevance of this concept to the objectives of our conference resides in the biosocial principle that defects and handicaps which concern us represent failure at this point in time of the human species to achieve a uniformly normal developmental sequence; and in our social structure, these catastrophic defects must be considered as societal defects representing the human species which mandates social obligation to provide the best comprehensive medical care possible and appropriate education and vocational training without any kind of civil right violation. This concept of total rehabilitation with maintenance of the civil rights of all without regard to race, creed, or financial resources is soundly based on biological and social principles of our time.

Varieties of Professional Care Organizations:

If one bears in mind the diversity of chronic diseases whose commonality is physical handicap, it becomes evident that no single physician is capable of providing the diverse types of specialized medical care required. Representatives of every medical speciality have special skills which are essential to a comprehensive medical care program. Furthermore, all allied medical professionals including geneticists, special educators, and vocational counselors are vital to comprehensive rehabilitation programs.

The numbers of public and private agencies, associations, foundations, and the interrelationships of hundreds of government agencies almost defy one to derive a meaningful concept of the extent of the clinical care and research support available in behalf of any one type of handicapping condition.

The Easter Seal Society, which established many of our first community-based rehabilitation centers for children, has supported research on physical handicap through its Easter Seal Research Foundation and has sponsored many pieces of federal legislation in behalf of our nation's handicapped population. This national organization has active chapters

in all of our states and is effective in many of our smallest communities. Their broad background of experience and understanding of federal legislative programs in the health field makes the Easter Seal Society a most effective advocate for all handicapped children and adults.

The National Foundation is the successor to the National Foundation for Infantile Paralysis, whose intensive research effort eradicated paralytic poliomyelitis from the Western world. The primary focus of its research and clinical evaluation program is on birth defects.

These two organizations deserve our special commendation for their efforts in behalf of all of our nation's handicapped and have assured me of their readiness to provide all support possible to assure the success of the White House Conference.

These somewhat extended remarks are offered with the hope that the White House Conference delegates will look upon the problem of physical handicap as a common entity, avoid effort to select a causative entity for special attention, but look upon deficiencies in care programs, discriminations and quality of living factors which are common to all types of physical handicap.

SUMMARY ON TREATMENT

PART II

TREATMENT OF THE MENTALLY RETARDED

The term "mental retardation" refers to impairments in intellectual ability and socio-adaptive behavior. It is both a symptom of an underlying developmental disorder and an assessment of an individual's potential ability to learn. Thus, the retarded individual learns relatively slowly, and at chronological maturity his capacity to understand and adapt to social-vocational challenges will be, to varying degrees, less than average.

Unfortunately, many of the earlier definitions of mental retardation were couched in extremely negative terms. These terms not only set the mentally retarded apart from other members of society, but also conveyed to many people visions of "subhuman" status, seriously restricted ability to develop or learn, and prolonged dependency--all of which could be used as justification for: a) not providing services, b) custodial care, and/or c) overprotection. Thus, negative "self-fulfilling prophecies" have been generated which have operated against successfully maximizing retarded person's levels of functioning. For example, once a severely retarded individual has been labeled as "custodial", living and learning environments are likely to be so structured as to reflect the predictions implied by that label, thereby precluding his progress to a more advanced level of functioning. Hence, although the process of categorization and classification is basic to clinical transactions, in the case of the mentally retarded, labels have frequently been used as a rationale for exclusion from benefits and services which are ordinarily available to non-retarded persons.

The symptom of mental retardation presents a unique challenge to the person so afflicted and his parents, as well as professionals who seek to habilitate the retarded citizen while strengthening overall family adjustment. Retardation is a major health, educational and social challenge for our country since it represents the most frequent handicap of childhood.

In our country the beginnings of enlightened treatment programs in mental retardation revolved around the humanitarian efforts of Dr's. Edouard Seguin and Samuel G. Howe in the mid-nineteenth century. They were active in assisting the states in establishing schools and residential centers. However, the effectiveness of their efforts was blunted by the basically rural population distribution of our country at that time, the dearth of training centers for producing a large

cadre of well-trained personnel, and the lack of an advocacy movement to spur the development of extensive service systems.

In the latter portion of the nineteenth century, several factors eventuated in a tragic interlude for the retarded which was to persist until 1960. In brief, the rapid acceptance of Binet's test of intelligence as the "only needed" assessment to label one as retarded, over reliance on brain pathology as the major cause of retardation, and a number of pseudo-scientific "genetic" family studies presented the retarded as dangerous social misfits and gave rise to the catch phrase "The Menace of the Feebleminded." As a result, the previous vibrant beginnings of effective treatment endeavors in our country gave way to a half-century of building huge institutions which placed a premium on low budgets, bench-sitting, and protecting society from its "deviant" retarded members. Massively overcrowded and grossly understaffed, the institutions became human warehouses--a far cry from their initial concepts and focus on humane treatment.

The burgeoning current national interest in the mentally retarded can be traced to the establishment of the National Association for Retarded Citizens (NARC) in 1950 as a citizen advocacy group to spur change in the field, and the creation of President John F. Kennedy's Panel on Mental Retardation and the subsequent federal mandate in 1963. For example, NARC has been a pioneer in initiating educational, vocational, and residential models across our country and then prompting local, state and federal levels of government to accept these services as part of their generic service aids to all retarded citizens. NARC has recently turned its attention to actively litigating for sweeping changes while steadfastly monitoring what they initiated. Similarly, members of President Kennedy's Panel on Mental Retardation, in their 1962 report, outlined 99 recommendations on what had to be done on a national scale and then helped to develop the rationales for the establishment of: (a) alternative models of care, (b) Mental Retardation Research Centers for the evolution of research knowledge and (c) the University Affiliated Facilities for training professional workers on behalf of the mentally retarded.

Mental retardation has been championed by our last four Presidents. Recently stated (1972) Presidential goals include a strong focus on the prevention of mental retardation and a de-institutionalization focus wherein a significant proportion of the over 180,000 retarded individuals in public institutions will be able to return to useful lives in their communities. The recently completed President's Committee on Mental Retardation report, entitled Mental Retardation:

Century of Decision, clearly enumerates what must be accomplished during the remaining years of this century to bring equal rights to the retarded. This report is a clarion call, replete with specific recommendations for treatment and habilitation. Viewed in these historical perspectives, the treatment and habilitation of the mentally retarded stand today at a most exciting point in the evolution of professional and citizen involvement.

The President's Committee on Mental Retardation (1976) noted that 89 percent of all mentally retarded persons are mildly retarded, six percent are moderately retarded, 3.5 percent are severely retarded and 1.5 percent are profoundly retarded.

The mildly retarded are almost always capable of learning to do productive work, learning academic school subjects to varying degrees and, as adults, living independently and becoming self-supporting if they have received appropriate services during childhood, adolescence and early adulthood.

Moderately retarded persons can almost always learn to care for themselves, profit in varying degrees from classroom instruction and be trained for semi-complex vocational tasks. With an appropriate background of stimulation and training from early childhood, most are able to become at least partially self-supporting and are able to live in the community with some degree of supervison.

Severely retarded persons generally require specialized services at all stages of their lives. They are capable of learning to care for themselves, and many can become marginally productive, as adults, under supervision in sheltered work settings. Recent studies, both in America and abroad, certainly demonstrate that the severely retarded are capable of performing many tasks which were previously thought to be beyond their capability.

The profoundly retarded nearly always require major inputs of medical and/or nursing supervision in order to remediate physical-medical disabilities and maintain life. Yet many can be taught some degree of self-care skills such as feeding and dressing.

Many outstanding developments in refined diagnostic approaches have been recently attained. Genetic counseling of prospective parents has enlarged the vista of prevention. Evaluation of the fetus in utero (via amniocentesis) has now evolved into a safe technique by which thirty-five different causes of mental retardation can be detected. This crucial information permits the parents to make

scientifically-based decisions about their future child. Although this topic is fraught with much religious controversy today, it should be noted that amniocentesis is very often a life-giving procedure--especially for couples who are afraid to initiate pregnancy because of a known high-risk. Similarly, new assessment techniques in the newborn period have evolved to the point where a new branch of pediatrics--neonatology--stands ready to evaluate, in the early hours and days of life, a wide number of conditions which can be ameliorated. The nationwide expansion of mandatory screening early in life for the inborn errors of metabolism (e.g., phenylketonuria and galactosemia), infectious diseases (e.g., syphilis and cytomegalic virus) and toxic substances (e.g., lead and abused pharmaceuticals) continues to hold promise for rapid diagnosis and effective treatment.

In spite of the recent giant strides in early diagnostic evaluation, expansion of the federally-funded Early and Periodic Screening, Diagnosis and Treatment Program is desperately needed. First initiated in 1967, this program has had more than its share of implementation problems. For example, as of June, 1975, only 3-1/2 million children (out of a possible 13 million eligible) had received their first screening evaluation. Yet the impact of early diagnostic and accompanying prescriptive-treatment approaches hold great promise for all handicapped children.

Treatment

The hopelessness regarding the treatment of mental retardation which prevailed twenty-five years ago has been vitiated by the encouraging results of numerous basic and applied studies which have documented what can be done.

Future Service Challenges

Research advances must be accompanied by an equally vigorous commitment to narrowing the gap between scientific discovery and clinical practice, including reduction in the delay of new applications while protecting consumers from premature application of new procedures and technology. For instance, it is estimated that a 50% reduction in the incidence of mental retardation could be realized if current knowledge were fully implemented.

A major challenge will be the orchestration of the highly diversified services required by retarded persons. They are in need of the same basic health services as other citizens, and hence they must have ready access to complete health programs without categorical discrimination. For example, they must have the same access to dental or mental health services as other citizens. In addition to acute medical needs, many retarded persons have chronic medical

problems which can be considered "catastrophic" conditions. Examples include the cardiovascular difficulties associated with Down's syndrome, epilepsy, cerebral palsy, sensory deficits, chronic disturbances of metabolism and many other conditions. Specialized services may at time be required. Meeting these very important medical needs of retarded persons does not, however, address their total developmental needs. As described above, developmental programs delivered by multi-disciplinary teams in as normative a setting as possible are essential to the amelioration of mental retardation. It follows that meeting the health needs of retarded persons involves much more than the delivery of medical services, and that it is a life-long process requiring a broad continuum of community-based services delivered by a wide spectrum of professionals.

SUMMARY ON TREATMENT OF THE MENTALLY HANDICAPPED

PART III

TYPES OF TREATMENT APPROACHES

A variety of different methods and techniques have been developed to ameliorate and treat mental disorder in its diverse forms and levels of intensity. Some have been practiced for decades; others have just become prevalent in the last ten years. In general, the categories of approaches are as follows:

1. Psychosocial

   The various psychotherapies which can be grouped under "psychosocial treatment" are premised on the belief that thought, mood and behavior can be influenced by verbal and symbolic interactions between a therapist skilled in such techniques and the disturbed and suffering person.

   Though psychoanalysis and psychodynamic therapy have traditionally formed the foundation of the treatment of mental illness, they have also been the most difficult to assess scientifically and to verify.

2. Behavior Therapy

   Behavior therapy is different from psychosocial approaches to mental illness in that its philosophy and techniques grew out of research on classical and operant conditioning. Rather than attacking the roots or the causes of mental disorder, the behavioral therapist attempts to alter the visible signs of the disturbance or dysfunction by systematically manipulating the conditions which are believed to produce or reinforce behavior.

   In institutions, this form of therapy has been successful in altering the behavior of psychotic adults and autistic children. It has been especially useful in reducing self-destructive behavior such as head banging, self-laceration and refusal to eat. However, there are increasing indications that some behaviorally instituted changes do not generalize from institutions to alternative living arrangements in the community.

3. Somatic Therapy

   Somatic therapy assumes that behavior can be influenced therapeutically by nonpsychological methods. The major

instrument of somatic therapy today is the psychotropic or psychoactive drug. With the perfection of these drugs over the past two decades, it is now possible to stabilize the condition of many schizophrenic and seriously disturbed persons thus eliminating the need for prolonged institutionalization in many cases.

Though psychotropic drugs do not "cure" mental illness, they do make it possible to reduce or eliminate the acute "episodes" of psychotic or disturbed behavior thus making it possible for many individuals to reside in less restrictive environments such as halfway houses, foster homes and their own homes. Unfortunately, however, long term use of drugs categorized as phenothiazines has been shown to result in the development of facial twitching in 3% to 40% of cases studied. Additionally, the problem identified has no known cure.

Another form of somatic therapy is electroconvulsive therapy or "shock" treatment. Though the use of ECT has been reduced in the past decade, some maintain that it is still the most effective and most rapid-acting treatment for the relief of the symptoms of severe depression in manic depressive psychosis and other disorders. It is increasingly apparent, however, that ECT has doubtful utility in the treatment of character disorders, schizophrenia and other disabilities which are not accompanied by serious depression.

As research into the genetic and biological factors which contribute to the onset of mental illness yields more precise findings, it is conceivable that the uses of chemical and biomedical methods of treatment and identification of mental disability will increase in importance. However, the complicated inter-relationships between possible biological antecedents and the effects of desocialization on the individual will require more than medication to resolve.

4. Other Techniques

Within the past decade there has been a dramatic increase in the use of new treatment techniques including methods which in one form or another are ages old. They include megavitamin therapy, "biofeedback," transcendental meditation, acupuncture, encounter groups and other techniques associated with the "human growth" movement; primal therapy, reevaluation counseling, and many more. Research on these new methods has been inadequate and very little hard data is available on the efficacy of any one approach.

Special Concerns

Within that portion of the population who may need mental health treatment, there are some groups whose specific problems require special emphasis:

1. Children

   During the past decade, the inadequacy of mental health treatment services for children has been continually brought to the public's attention. Though services have been expanded during this period, they are still woefully inadequate. There is a continuing need for more day treatment centers, residential programs, special education services, specialized foster homes, etc.

   Two bright spots, however, have begun to emerge, First, the "right to education" movement could mean that many mentally disturbed children who previously had to be institutionalized because they were excluded from public schools, will now receive an education in their home communities. Coupled with the right is an increasing effort to take disabled children out of the isolation of special classes and to "mainstream" them into normal classrooms to the extent possible.

   Second, the emphasis on early identification and intervention in a variety of childhood handicaps should hopefully bear fruit in the reduction of mental disability in older children and adolescents.

2. Elderly

   A significant portion of persons residing in state institutions for the mentally ill are over 65 years of age. Though many have been there for several years, others are admitted in later life as a result of senility and other disturbances associated with old age. Many of these individuals are not necessarily mentally ill, but are rather dependent persons with no where else to go. Research into the treatment of aging-related disabilities is inadequate and few dynamic programs for such persons exist around the country.

3. Minority and Low Income Persons

The difficulty of determining the appropriateness and efficacy of treatment for this group is particularly great. Prejudice and difficulties in communication play a role; so, often, do poverty, malnutrition and unemployment. In poor communities, the first identification is usually made by the police. Symptoms are sometimes called neurotic in whites and psychotic or psychopathic in blacks. Third generation white patients are accepted for psychotherapy significantly more often than people of the same socio-economic class who are blacks or Mexican Americans.

In spite of some research indicating the value of psychotherapy with lower class outpatients, basic questions remain about the best kind of treatment for members of particular ethnic or socio-economic grups and about the best way to persuade them to come for treatment and remain in treatment.

Continuity of Treatment Programs

Though a variety of services for the mentally ill currently exist in many communities there is still a need to link these services together in a coherent pattern to assure that patients are not "lost in the cracks". Such a continuum will also assist in the ability of the system to respond to the changing needs of the patient as he moves from lower to higher levels of emotional functioning.

PART IV

VISION (EYE CARE AND TREATMENT)

An estimated ninety-four percent of Americans sixty-five years of age or over have subnormal binocular visual acuity in need of correction as compared to forty-six percent of the general adult population. More than ten million children need eye care, and their future is only as bright as the leaders of the generation are able to make it by minimizing physical impairments or other handicaps to their health.

The prevalence and degree of visual impairment of persons with a family income of less than $5,000 is considerably higher than corresponding rates for any other income group, regardless of age. Up to eighty percent of delinquents and semi-delinquents studied by the White House Conference on Juvenile Delinquency had learning difficulties, and poor vision was found to be a contributing factor in fifty percent of these cases.

The challenge to preserve the vision of all Americans falls upon all citizens, and a public awareness of the role which effective vision can have on the enrichment of each individual's life must be realized and accepted. Partially sighted and legally blind individuals must first be located; then they must be given treatment which can improve vision and advised of the facilities and services available to them.

Dentistry for the Handicapped

Dental disease represents a major health problem experienced by many, if not all, handicapped citizens. Many studies have reported on the incidence and devastating effects of oral pathology among individuals with mental and/or physical disabilities. Handicapped citizens as a group find dental treatment difficult to locate and purchase. Although the delivery of dental health services to handicapped children is insufficient, it is further diminished for handicapped adults. The lack of education both of dentists and parents is related to the unfortunate level of oral disease experienced by handicapped individuals.

Approximately 4,000 dentists graduate from dental schools each year who are not sufficiently trained to provide proper dental treatment to people with various handicapping conditions. An innovative development is noted which is designed to ameliorate this apparent deficit in manpower. The Robert Wood Johnson Foundation has awarded 4.7 million dollars over a three-year period to ten dental schools. The purpose of this award is for curriculum development and training of dental students in the care of handicapped patients.

Rehabilitation Engineering

In the field of rehabilitation, the major goal is the return of the patient to a stable way of life in which the handicapped individual may achieve the maximum in both vocation and in avocation. In recent years, we have witnessed the emergence of the rehabilitation team. This team is interdisciplinary in its composition including medical and allied health personnel, dental personnel, engineering and allied personnel, experts in psychology, social science and vocational rehabilitation and, of course, the patient and his family. Since the care of the patient is the prime purpose of rehabilitation teams, the physician must take final (legal) responsibility, but major areas of leadership are normally delegated to other team members.

The Rehabilitation Act of 1973 provides for the establishment of rehabilitation engineering centers by the Department of Health, Education and Welfare. Centers organized in response to this legislation provide total rehabilitation engineering care and treatment of patients supported by research and development, evaluation and educational activities. Six have already been established.

The system will become much more responsive as the number in the network increases and when the network is tied together by a managerial structure. The formalized integration of the HEW rehabilitation engineering system with that of the V.A. will mean even more effective and more responsive delivery of rehabilitation engineering services to all.

A major problem exists in the educational sector. Funding support for established educational centers and universities has been difficult to acquire to enhance preparatory and post-graduate educational programs. Therefore, as rehabilitation engineering capability progresses in a few centers with active development and technology applications programs, national uniformity is not achieved. A serious lag exists in the introduction of the technology in the clinic to benefit patients nationally.

Disabled persons through special educational programs can and should enter positions at all levels of clinical engineering, including the support, technical services and management. Many centers now specializing in rehabilitation engineering depend heavily on the capabilities of disabled managerial and professional staff. Increase is needed in the capability and scope of existing educational programs throughout our society to make available that knowledge of rehabilitation engineering needed by any entering the field and wishing to upgrade their ability continually.

PART V

MATERNAL AND CHILD HEALTH SERVICES AND CRIPPLED CHILDREN'S PROGRAM - DHEW

Background History

The Maternal and Child Health program, DHEW, is responsible for extending and improving health services for mothers and children, especially in rural areas of the country. These programs are designed to reduce infant mortality and also to provide maternal and child health care, with an emphasis on preventive services in low income areas.

The program activities of both maternal and child health and crippled children have evolved and expanded as national awareness of problems grew and as the medical technologies developed to treat these problems. For example: in 1951 Regional Centers for the treatment of congenital heart disease were established; in 1963, in an attempt to reduce infant and maternal mortality and the incidence of mental retardation in high risk groups, maternity and infant care projects were initiated; in 1965 children and youth projects were begun; newborn intensive care projects were added in 1967; early detection, expanded outreach, and dental care, were added to the authorities under Title V in 1967; and in the early 70's Family Planning programs were included in the aggregate of service programs provided to mothers and children.

Congress, through Public Law 93-53, directed conversion of various special project grants to a formula grant program by July 1, 1975. This included the project grants for Maternity and Infant Care (MIC), Children and Youth (C and Y), Dental Care, Family Planning, and Intensive Infant Care.

Crippled Children's Services

Formula grants are awarded to State crippled children agencies for locating children who are crippled or who have conditions leading to crippling, and to provide them with medical, surgical, corrective, and other care and services that are necessary. Every State has a crippled children's services program, and State law either defines the crippling conditions to be included or directs the crippled children's agency to define them. All states include children under 21 years of age who have some kind of handicap that needs orthopedic or surgical treatment.

As is the case with the State Maternal and Child Health Services program, each State Crippled Children's Services program must be under the direction of a physician and must comply with Federal regulations including several designed essentially to assure: (1) a high standard of care, including high standards for those personnel and facilities which are to be used in the provision of services; (2) that health care services to be provided are comprehensive in nature and (3) that there will be development, strengthening and improvement of standards, techniques, and services.

Since care of a handicapped child may be a financial burden greater than the parents can bear, the agency helps parents with financial planning and may assume part or all of the cost of care, depending on the child's condition, the family's resources, and the funds available to the State agency.

ISSUES

HEC V-1 In the field of treatment, how can we overcome the serious lag which exists between the generation of new knowledge and its general application in the field? (What immediate steps can be taken to insure that all programs are using new knowledge to benefit the handicapped?)

HEC V-2 How can funding be obtained for pre-service and in-service training?

HEC V-3 How do we organize programs for effective and efficient treatment?

HEC V-4 What guidelines and standards are necessary for quality treatment?

HEC V-5 How can handicapped persons participate actively in the development and implementation of treatment programs which affect them?

HEC V-6 How can handicapped individuals afford to pay for comprehensive and quality treatment in the face of rising costs?

HEC V-7 How can costs of treatment be reduced?

HEC V-8 How can we improve communications in the area of treatment among professions and between professionals, clients and parents? Families?

HEC V-9 How can we integrate the components of health care in order to insure that the treatment needs of clients and patients are being met?

HEC V-10 How do we establish as public policy the right of physically and mentally handicapped individuals to treatment?

HEC V-11 How can we remove the barriers (environmental, transportation, etc.) to treatment?

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